

Dear Madam Chairwoman Lee and members of the Senate Human Services Committee.

I am Deidre Hillman residing in District 32. I am providing my written testimony in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

My perspective comes to you today likely differently than many others. I have a healthy active 6-year-old girl. Although recently she's been diagnosed with learning challenges including dyslexia and dysgraphia, she comes from a home with two fulltime working adults. I operate my own business and my husband is employed by a private company. We are grateful we can flex our work schedules to take her to appointments which are minor compared to the families I have served over my 8 years as a volunteer at a few organizations.

One organization I volunteer with gifts ill or developmentally/intellectually disabled children a large gift either in the form of an experience, a trip or it can be an enhancement to their lives of some sort. Sometimes I work with the families of the child for months and years while we try to determine the best gift for their minor child. I get to learn so much from these families and I'd like to share my summary of what I've experienced.

I know more about our medical care and the lack of it in our surrounding communities. Often times the parents must take time off of work, to plan the travel and then to travel to Fargo, Sioux Falls, Minneapolis and Denver. In between those major appointments they must juggle local doctoring appointments for routine checkups, scans, physical therapy, occupational therapy, speech therapy and more. And these are all scheduled appointments when the health of their child is WELL. Now add on an infection, an allergic reaction, influenza or any other medical illness that can compromise these children with complex and extraordinary needs. Their whole planned appointment schedule goes out the door. Spiraling sometimes and pushing appointments out sometimes months. One appointment at a time must be moved.

On top of providing medical accommodations for the needs their child may have, they are trying to provide education to their child. I don't know how many of you are raising a child in school but this brings on a whole other list of coping, managing schedules, participating in the arts, sports or rehearsals for choir or dance. Helping with school fundraisers and PTO. It's maddening, rewarding and can become a parttime job for a working parent. But we all do it, because we want to be involved and we want the best for our children.

And then, they must go to work. Weekly and sometimes daily they must pass along the current medical needs or schedules from one staff member and specialist to the other. Sometimes a minor sibling is depended upon to help with this.

These parents truly are my heroes.

I believe in many instances when I ask the parents how they do it all, they have become numb to the lack of support, they believe there is no other option yet they remain hopeful that staffing of suitable support will get better "one day".

The parents know their children best and could possibly expedite development and advancement in the children. We know there is a shortage of skilled caregivers and has high turnover. Each time a child meets a new caregiver, they have to get to know each other, causing gaps in their development. If the parent could be paid to stay with the child, the child would have consistency and trust would be high.

Thank you for this opportunity to have my opinion heard through my written testimony. I am sorry that I cannot be there today.

I urge you to vote yes on Senate Bill No 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need to help them now.

Sincerely,

Deidre Hillman

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